



# To inform or not to inform?

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## MEDISINSK ETIKK

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A new information dilemma has arisen for doctors in public hospitals: Should they inform cancer patients that costly private treatment options are available?

In the public health services, prioritisation is a virtue born of necessity if they are to succeed in fulfilling the ambition of helping people enjoy the greatest possible number of years of life, distributed fairly (1). This may entail that effective therapies remain unused because the effect is minor and the costs are high. It came as an unexpected challenge to the Norwegian debate on prioritisation when the private Aleris hospital started to provide cancer therapies that have been rejected by the Decision Forum for New Methodologies for use in public hospitals. Oncologists employed by the public sector are thus facing a new ethical challenge: Should they inform their patients about an effective therapy that the public sector has chosen not to provide, but that Aleris offers? Moreover, is it ethically acceptable for doctors to assess their patients and inform only those who can reasonably be expected to have the ability to pay?

In 2017, the Clinical Ethics Committee (KEK) at St. Olavs University Hospital were presented with this issue, which was deliberated in accordance with a structured model for ethical analysis (2). In this article we present the committee's assessments.

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## Model for systematic deliberation of ethical dilemmas

- What is the nature of the ethical dilemma?
- What are the facts of the case?
- Who are the parties concerned and what are their interests?

- Which values, principles and statutory regulations are involved? What is at stake?
  - What alternative courses of action are available?
  - Summary/conclusion
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## The facts of the case

In a report on ‘the two-tier health services’, some oncologists warn against the trend towards bisection, while describing how they choose whether or not to inform their patients about private treatment alternatives (3). Senior Consultant Stein Harald Sundstrøm told the VG daily: ‘... I assess the patients [...] It’s difficult if a patient will have to sell their house, their holiday home and their car. If they obviously can’t afford it, I don’t inform them about such options’ (3).

A newspaper reader reacted to this statement and sent a message of concern to the County Governor of Trøndelag. The reader was concerned that patients were treated differently in terms of the information provided to them, and that some patients may thus have had their lives unnecessarily cut short. The lawyers in the Governor’s office considered the matter, including whether the Patients and Users’ Rights Act obligates the doctors to provide information. They concluded that the legal position was possibly unclear. The case was submitted to St. Olavs University Hospital and its Clinical Ethics Committee and reported to the Medical Ethics Council.

## The parties concerned

The issue has been raised to the level of principle, and thus is not directly linked to a specific case involving a patient. In general, information on life-prolonging treatment options, or the withholding of such information, may affect the health, life quality and life situation of cancer patients. The doctors are also a party to the matter – the issue of information is intimately linked to what is considered appropriate professional conduct. In addition, it can be claimed that the more vaguely termed ‘society’ is an involved party, since this is a matter of principle that concerns the relationship between publicly and privately funded treatment.

## The values at stake

The duty to inform has an important status in Norwegian health services, legally as well as ethically. It constitutes a precondition for the exercise of patient autonomy. Information provides the individual patient with authority and autonomy, and without it there can be no real self- or co-determination. The statutory basis for the duty to inform is incorporated in Section 3.2 of the Patients and Users’ Rights Act: ‘The patient shall have the information that is necessary to obtain an insight into his or her health condition and the content of the health care’ (4).

The idea of equal status is another pillar of the Norwegian health services. Everybody is entitled to the same health services, irrespective of their status, place of residence or financial situation. In addition to equal status, equality may also be regarded as a key value. Norwegians react strongly to discrimination in the health services.

Trust is a fundamental value in the doctor-patient relationship. It may be put at risk if potentially valuable information is withheld. The doctor is expected to be the patient’s advocate, but the patient also trusts the doctor to fulfil the role of expert and care provider. This may entail acceptance of the doctor taking decisions on the patient’s behalf, without unloading all information and choices onto the patient.

‘Beneficence’ and ‘non-maleficence’ are two core principles of medical ethics. In legal statutes, this is reflected in the requirements for professional reliability and considerate

care laid down in the Health Personnel Act. Absence of information may cause harm and prevent beneficence. However, 'non-maleficence' may point in the opposite direction. Information that the patient cannot make any practical use of may possibly cause harm. In medical research ethics, the concept of 'informational harm' has been established, for example related to unintended research findings of incurable conditions. In fact, the Biotechnology Act prohibits predictive genetic testing of children unless there is a prospect of health gain. Good medical practice may thus be claimed to include a portioning and positioning of information when it is observed that this information may cause harm to the patient (5).

Universal health services that serve everybody according to their needs is a fundamental ideal in Norway. For the system to survive, the patients and the general public must be confident that the public health services will come to their aid when they really need help. In addition, it is crucial that the priorities enjoy democratic support, i.e. that the population understands the necessity of the prioritisations that are made and endorses them. This presupposes transparency.

## Deliberation of alternatives

When the public health services cannot provide life-prolonging treatment which is available in a private hospital, the doctor has three alternative courses of action:

1. Inform the patient that a private treatment option exists.
2. Not inform the patient that a private treatment option exists.
3. Inform some patients, but not others, based on an individual assessment as to who will benefit from this information.

The committee realises that there may be good reasons for not informing patients about private treatment options. The information may put the patient in a difficult situation, the family's finances and stability are at stake, and the gain to be had in terms of treatment is not very great in any case. Providing good-quality information is time-consuming. Loyalty to public healthcare provision may indicate that the duty to inform primarily encompasses what is regarded as appropriate treatment within the public health services.

At the same time, some patients who are well able to pay and have a strong desire to prolong their life at its final stage may obviously benefit from the information. If doctors are able to determine who these patients are, they appear to be applying a personalised information strategy. This was the position that Dr Sundstrøm defended. Its weakness, as seen by the committee, is the challenge involved in distinguishing between the patients. Patients' ability to pay is not written all over them. The likelihood of making an error is high, and regardless of the outcome, the patients may feel that such concealed assessments on the doctor's part will amount to a violation of their autonomy. Today, patients with no ability to pay may also benefit from information on costly forms of treatment (6). A number of Norwegian patients have started fundraising campaigns on Facebook to pay for treatment in Norway or abroad. The patient may appear in the media to use his or her case politically in an attempt to sway the Decision Forum, politicians or others. Even without any ability to pay, they will have some scope for action.

The choice to inform some, but not all patients arises from an honourable intention of professional ethics to carry out good medical practice. In this specific case one may ask, however, whether this principle will prevail in the encounter with key values in Norwegian society, especially the idea of equality. One issue is that the two-tiered healthcare system, with private payment for costly cancer therapies, violates this value. It may be even worse for the patients to feel that they are treated unequally by the public health services when

patients with the same disease receive different information from their doctor.

This equality argument has parallels with the conclusion drawn by the Clinical Ethics Committee at Haukeland University Hospital, which in 2015 argued that public hospitals should not administer cancer treatment paid for by patients themselves (7). A situation could then be imagined where two patients with the same disease were admitted to the same oncological ward, but only one of them received life-prolonging treatment. Patients with identical diseases should receive the same treatment by the public health services. The matter was submitted to the Ministry of Health and Care Services, which drew the same conclusion: '... treatment of patients with self-financed drugs that have been excluded from use or are under consideration by the Decision Forum may undermine the principle of equal provision of health services' (8).

The committee realises that information on costly private treatment with limited effect may have a negative impact on the life of some patients. Instead of abandoning medical treatment when the public services have nothing more to offer, patients may eventually upend their family's finances with very limited benefit and perhaps even major adverse effects. With good dialogue between the therapist and the patient, such damage should be preventable. Patients must be assumed to be able to take a critical view of costly cancer therapies with limited effect and what would be the right thing to do to maintain the quality of life at its final stage.

Another argument in favour of informing is that the dilemma we are facing here is a direct result of a deliberate prioritisation in the Norwegian health services. In the debate on prioritisation in recent years, the need for open and democratic priorities has been highlighted. As an illustration, the slogan launched by the Norheim Commission was 'Open and fair' (1). In a universal health service that belongs to us all, it is desirable that as many as possible understand the need to prioritise, and participate in the discussion of the criteria. In the name of openness and democracy, it is essential that patients who are not offered treatment for reasons of prioritisation at least gain insight into the processes in which they are involved.

## Conclusion

This case involves questions of principle, and the number of such cases is likely to grow. It can be expected that the public health services will increasingly need to disallow new forms of life-prolonging treatment, at least until they can be obtained at a lower price. This issue assumes a special character in Norway, given the dominant position held by the public health services and the absence of a tradition for private hospitals to provide advanced cancer therapies, for example.

The Clinical Ethics Committee at St. Olavs University Hospital concluded that the hospital would stand on firmer ethical (and legal) ground by providing information to all patients. Obviously, if patients have no desire to receive in-depth information, their wish must be respected. As a matter of principle, however, everybody should be able to decide whether or not they want to be informed about private alternatives. Consequently, if patients themselves do not broach this topic, the doctor should. This position will best safeguard the many different ethical concerns that are at stake in the Norwegian context, even though it obviously comes at a price in terms of ethics.

Some may object that this conclusion paves the way for a virtually limitless duty to inform in public hospitals. But does it really? The therapies referred to here have a documented effect, they are approved in Norway and are provided in domestic hospitals. If we envisage that all these criteria ought to be fulfilled before the duty to inform arises, it seems manageable.

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Published: 4 September 2018. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.18.0265

Received 20.3.2018, first revision submitted 16.5.2018, accepted 27.6.2018.

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